



Listening Session Summary

2005 White House Conference on Aging

Date: December 8, 2004

Location: Hyatt Regency Hotel, Chicago, Illinois

Record of Attendance

WHCOA Policy Committee members present included: Alexandro Apparicio, M.D. and Robert Blancato

WHCOA staff member present: Remy Aronoff

Total registered participants: 137

Total participants registered to testify: 32; total attending: 31

Host and Co-Sponsors

The Listening Session was hosted by the Illinois Department on Aging during the Governor's Conference on Aging and co-sponsored by the Illinois Association of Area Agencies on Aging (I4A) and the Illinois Coalition on Aging. Matt Wescott was the IDoA liaison and Mike O'Donnell was I4A liaison for the Listening Session.

Format and Recording

Testimony was given by 31 presenters. Each presenter submitted written testimony in advance and was allotted 3 minutes for oral testimony. Presenters were given the opportunity to provide additional written testimony and documentation in response to questions from the Policy Committee members and staff. The proceedings were recorded by a CART (Communication Access Realtime Translation) reporter from Caption First, Inc.

The Summary Report was prepared by Mike O'Donnell.

Call to Order

The Listening Session was called to order at 9:30 a.m. Mike O'Donnell introduced the members of the WHCOA Policy Committee and presented the guidelines for the proceedings.

Introductory Remarks from the WHCOA Policy Committee

Dr. Apparicio chaired the Listening Session. He thanked the Illinois Department on Aging and the co-sponsors and introduced Bob Blancato. Mr. Blancato presented an overview of the 2005 White House Conference on Aging and urged presenters to address important aging and boomer issues requiring national attention over the next 10 years. He urged everyone to prepare and plan for the future of an aging America.

Summary of Testimony

1. **Charles Johnson**, Director, Illinois Department on Aging welcomed everyone. He emphasized the importance of active listening in the development of public policies and programs and urged people to express their opinions on issues affecting older persons today and in the future.
2. **Bob O'Connor** testified on behalf of the Illinois Council on Aging that comprises 23 citizen members and eight members of the Illinois General Assembly and advises the Illinois Department on Aging.

The Council has developed a list of 28 priority issues; improving pharmaceutical assistance programs, increasing wages for direct care workers, integrating systems for health care, health promotion and disease prevention; improving the quality of nursing home care; assisting family caregivers through additional education and increasing funding for respite care; and funding and coordinating senior transportation services.

3. **Adrian Mary Charniak**, a grandmother raising four grandchildren, offered recommendations to assist grandparents and other kinship caregivers that included establishing a national 1-800-GRANDMA phone number to provide information and assistance on custody, guardianship and adoption, and referrals to supportive services in each state. She also recommended early intervention programs for children affected by substance abuse, affordable housing options for grandparents raising grandchildren, increasing financial support to grandparents raising grandchildren and other relative caregivers through the Temporary Assistance to Needy Families program, and providing educational assistance to children raised by grandparents and other kinship caregivers.
4. **Terri Worman** and **John Dinauer**, co-chairs of the Chicago Task Force on Lesbian, Gay, Bisexual and Transgender Aging urged the 2005 WHCOA to include Lesbian, Gay, Bisexual and Transgender seniors as a group, and address its issues and needs across the aging service provider network. There are an estimated 40,000 LGBT persons 55+ in the City of Chicago. Their issues mirror those in aging generally including affordable housing, affordable health care, and home and community-based support services. They recommended more inclusive language and training on understanding and serving LGBT seniors as an integral part of any elder-specific cultural competency training program for professionals in the health care and helping professions.
5. **Paul Bennett**, Director of the University of Illinois Chicago's West Central Case Management Unit, a service project of the Jane Addams College of Social Work, addressed the issue of Naturally Occurring Retirement Communities (NORC) where 50 percent of the residents are over the age of 60 and are aging in place. He recommended that funding of future community-based services recognize the strengths inherent in the concepts and structural frameworks of the NORC as an elder-friendly community where older persons can successfully age in place.
6. **Deb Penn**, President of Autumn Accolade, Inc. addressed the need for reforms in long-term care. She raised concerns about the lack of access to home and community-based support services in rural areas. She recommended the development of affordable assisted living facilities to enable older persons to age in place in the least restrictive setting with appropriate supportive services. She also recommended using information technology to educate caregivers about appropriate options for their older relatives.

7. **Dr. Donald Jurivich**, Associate Professor in the Department of Medicine at the University of Illinois and Section Chief for Geriatric Medicine, called for expanding educational programs in geriatric medicine. He stated that Illinois needs at least 300 geriatricians, but less than 10 percent of that goal has been realized. He called for legislative steps in Congress and in the Illinois General Assembly to enact malpractice reform, increase funding for geriatric medical training, promote interdisciplinary health care teams, and create Centers on Aging in each state to address education, research and clinical services for aging citizens.
8. **Chris Myrick**, representing Wyeth Consumer Healthcare, addressed the role of multivitamins to help prevent heart disease, certain types of cancer, osteoporosis, cataracts, and macular degeneration. He recommended the use of a daily multivitamin to supplement food in-take.
9. **Nancy Nelson**, Executive Director of the Illinois Home Care Council, described the services provided by her member agencies that include skilled nursing, physical therapy, occupational therapy, home health aides, speech and language therapy, medical and social services, durable medical equipment and hospice care. She noted that home health services are providing very technical, complex services in the home. Last year, about \$450 million was spent in Illinois for home health services for over 3 million visits to 115,000 patients. She recommended increasing reimbursement for home health services commensurate with the complexity of the services provided, adequate reimbursement for the provision of home health services in rural areas, and adequate payments for durable medical equipment.
10. **Kathleen Quinn**, representing the National Association of Adult Protective Services addressed the need for a comprehensive national response to elder abuse, neglect and financial exploitation. She pointed out that Adult Protective Services are the only public services authorized and empowered by state laws to respond to and investigate allegations of abuse and neglect, and exploitation of older and vulnerable adults. She noted the disparity between \$4 billion in annual federal spending on child abuse services compared to \$5 million in federal spending for public awareness and prevention of elder abuse, not victim services. NAAPS recommends that the WHCOA address the problem of elder abuse in state Adult Protective Services programs as a major issue. NAAPS recommends that the WHCOA use the Elder Abuse Policy Summit recommendations developed by the National Center on Elder Abuse and the proposed Elder Justice Act as starting points for discussion of elder abuse in APS and include representatives from NAAPS and Adult Protective Services in the White House Conference on Aging process.
11. **Margaret Niederer**, representing the Illinois Retired Teachers Association Foundation, addressed the protection of people in long-term care facilities and community-based settings. She made the following recommendations: (1) stronger enforcement of laws and regulations to protect long-term care consumers; (2) empowerment of professional Ombudsmen and recruitment and training of more volunteer community Ombudsmen; (3) sustain and support family councils and citizen advocacy groups; (4) reform the survey and penalty system; (5) cut funds to facilities where there is abuse and neglect; and (6) implement culture change models in long-term care facilities to improve quality of care and the quality of the lives of the residents.
12. **Barbara Gaskill**, representing the Illinois Association of Nutrition Programs, made the following recommendations: (1) reverse the decline in congregate nutrition programs for the elderly under Title III-C-1 of the Older Americans Act; (2) respond to seniors who need more than one meal a day and meals on weekends; (3) address the nutritional needs of seniors first before transferring funds from congregate nutrition or home delivered meals in order to address other needs of older persons.

13. **Jeffrey Blumberg**, Professor of Nutrition at Tufts University, recommended that older persons follow dietary guidelines and take a daily multivitamin. He noted randomized clinical trials and large scale observational studies to show that multivitamins can reduce the risk of age-related macular degeneration, colon cancer, peripheral arterial disease, myocardial infarct, and multiple sclerosis as well as enhance immunity and reduce infectious disease episodes.
14. **Deborah Kuiken**, Executive Director, Midland Area Agency on Aging, in Centralia, Illinois, described the Mental Health and Aging Systems Integration (MHASI) project serving the 29 southernmost rural counties of Illinois since 2002. With funding from the Illinois Department of Human Services, Division of Mental Health, the MHASI project has supported gero-psych specialists at community mental health centers and has implemented a behavioral health indicator check-list used in assessing older persons, identifying mental health issues and making appropriate referrals to qualified mental health professionals for treatment. She called for the training and recruitment of more geriatric psychiatrists especially in rural areas and urged the WHCOA to make mental health and aging a prominent issue on the national agenda for the Conference.
15. **Mike O'Donnell**, President of the Illinois Coalition on Mental Health & Aging, stated the number of persons 60+ affected by mental illness will double over the next 30 years from 7.5 million to 15 million. He made the following recommendations: (1) initiate a national educational campaign to eliminate the stigma associated with mental illness and aging; (2) increase funding for evidence-based practices and interdisciplinary training in geriatric mental health; (3) integrate adult mental health and substance abuse services with primary health care; (4) enact parity in private insurance, Medicare, and Medicaid to cover and reimburse mental health services; (5) develop more community-based residential treatment options which integrate affordable housing, treatment services and supportive services in the least restrictive settings; and (6) assure continuity of mental health services for residents of long-term care facilities.
16. **Joy Paeth**, Executive Director, Area Agency on Aging of Southwestern Illinois in Collinsville, spoke as President of the Illinois Association of Area Agencies on Aging (IAA). She addressed the need to build the base of support and strengthen today's system of supportive services to enable older persons and boomers to age in their homes and communities. She called for increased funding under the Older Americans Act to keep pace with the growth of older persons and family caregivers. She called for more partnerships between the Administration on Aging and the Centers for Medicare and Medicaid to address the needs of older persons with disabilities. She would also like to see collaborative efforts to ensure the integrity of the Medicare program and the implementation of real choice initiatives to carry out the state's Olmstead plan and enable older adults to remain in their homes.
17. **Jon Lavin**, Executive Director, Suburban Area Agency on Aging, addressed the role of Area Agencies on Aging and Older Americans Act programs in the system of long-term care. He noted that community-based programs providing supportive services and nutrition services help older persons to maintain their health and independence. He recommended that reauthorization of the Older Americans Act in 2005 should be a major issue addressed at the White House Conference on Aging.
18. **Wes Tower**, Chairperson, Corporate Board, East Central Illinois Area Agency on Aging based in Bloomington, Illinois, recommended that the Aging Network inform older adults, family caregivers and the boomers about programs and services available to help them live independently. He recommended adding a new Title VIII to the Older Americans Act to provide the resources to Area Agencies on Aging to assist local communities in preparing for the aging of the baby boomer population.

19. **Gilbert Nolde**, member of the Board of the Central Illinois Agency on Aging based in Peoria, recommended a national initiative to promote aging in place. He recommended helping older adults to rehabilitate their homes for handicapped accessibility, developing multi-generational neighborhoods, and improving access to community services. He called for a national initiative to spur the involvement of counties, cities, housing authorities, workforce development boards, public transportation authorities, regional planning entities, and private developers to plan aging-friendly communities.
20. **Joyce Gallagher**, Commissioner, Chicago Department on Aging, described the Chicago “Fitness Plus” program and the “Senior Wellness Program” which fosters a physically active lifestyle and positive health choices to optimize health, physical ability and functional capacity. The Chicago Department on Aging has recently established a Well-being Task Force, which includes public and private partners, to identify and assist an estimated 113,000-isolated older persons before their conditions deteriorate into serious problems. She also noted that this initiative has identified older persons with mental illness.
21. **Joanne Thomas**, Executive Director, Central Illinois Agency on Aging and co-chair of the Illinois Task Force on Grandparents Raising Grandchildren, made the following recommendations: (1) expand eligibility for services under Title III-E of the Older Americans Act to include grandparents under age 60 regardless of the age of the care recipient; (2) extend services to caregivers 60+ caring for adult children with developmental disabilities; (3) increase funding to provide a minimum of two days of respite per month for caregivers; (4) expand the definition of respite services to increase access to a variety of care options and service modalities; (5) initiate a national cooperative effort with the Department of Labor and local Workforce Investment Boards to assist employees with caregiving responsibilities; (6) form partnerships with educational institutions to develop caregiver support groups; (7) establish a national tax credit for caregivers; (8) expand the definition of OAA Title III-E “supplemental services;” (9) maximize the flexibility of OAA Title III-E to address the special needs of grandparents of all ages; and (10) provide funding assistance to state units on aging and Area Agencies on Aging to provide caregiver education, training, advocacy, program development and coordination at the state and local levels.
22. **Bob Costello**, with Robert W. Baird Company in Chicago, addressed Social Security reform, recommended putting a portion of Social Security payments into personal retirement accounts. He recommended enactment of HR 4895, the individual Social Security investment plan and stated that the goal of reforming Social Security should be a sound retirement system for every generation, designed with real savings.
23. **Karen Schainker**, President of the Association of Illinois Senior Centers, stated that senior centers are the one entity in the aging network uniquely positioned to assist seniors of all ages and economic levels in maintaining their independence. She noted that senior centers coordinate a variety of services and opportunities for seniors, which affect all the issue areas on the agenda for the 2005 WHCOA. She stated that senior centers should be elevated to a prominent position with direct funding to promote mental and physical wellness. She made the following recommendations: (1) provide specific funding for the operation of senior centers; and (2) recognize senior centers within the aging network as the entities already in place and positioned to build an even stronger foundation for home- and community-based services.
24. **Jerry Anderson**, Executive Director of Senior Services Plus, cited the enactment of SB 2880, the Older Adults Services Act, as model state legislation for the restructuring of the long-term

care system. He recommended that the 2005 WHCOA give priority to expanding and developing home- and community-based services for older persons in greatest economic and social need, especially homemaker services through the Community Care Program.

25. **Janet Ellis**, Executive Director of the Northwestern Illinois Area Agency on Aging based in Rockford, Illinois, addressed reauthorization of the Older Americans Act in 2005. She made the following recommendations: (1) expand opportunities and funding for the aging network; (2) maximize flexibility for local service delivery and reduce administrative burden i.e., a unified OAA Title III-C for meals; (3) maximize respite options for caregivers allowing AAAs to coordinate limited resources under OAA Title III-E with other funding streams at the local level; (4) use the 2005 WHCOA to acknowledge the status of today's services and benefits, their limitations, barriers and successes and build partnerships for the future; (5) recognize and support the Aging Network as the primary source of information and assistance for older persons in need of pharmaceutical assistance; and (6) use the 2005 WHCOA as a catalyst for educating the population on the needs and issues confronting an aging society.
26. **Melanie Chavin**, Vice President of Program Services for the Greater Illinois Chapter of the Alzheimer's Association, stated that in 50 years there would be an estimated 13.5 million Americans with Alzheimer's disease. She made the following recommendations: (1) protect funding for all state and federally funded home and community-based options to assist caregivers; (2) support quality training and innovative strategies for dementia care; (3) closely monitor quality of care in long-term care facilities and community-based settings; and (4) appropriate \$1 billion in federal funds for the National Institutes of Health to conduct research on the cause, prevention and cure for Alzheimer's disease.
27. **Rosemary Gemperle**, Executive Director of the Coalition of Limited English Speaking Elderly, addressed the needs among a growing number of immigrants and refugees in the community. She noted that community-based ethnic agencies, not Case Coordination Units, are providing most of the case management for older persons who are immigrants and refugees. However many of these agencies receive no federal Older Americans Act funds or state funds from Area Agencies on Aging. She stated, "Because our communities welcome and accept these new Americans into our society, we have an obligation to include them in our programs and services funded under the Older Americans Act."
28. **Jane Angelis**, director of the Illinois Intergenerational Initiative, spoke on behalf of the Illinois Board of Education and made the following recommendations: (1) begin a national dialogue between higher education and the aging network, i.e., a new program in Illinois that engages retirees from higher education as volunteers; and (2) encourage new and creative intergenerational partnerships to provide support to frail elders and decrease the isolation of elders in nursing homes.
29. **Kathy Deresinski** and **Angela Griffin** spoke on behalf of Retired and Senior Volunteer Program Directors, Foster Grandparent Program Directors, and Senior Companion Program Directors. They noted that 77 million aging baby-boomers are our only increasing natural resource. They recommended that America harness the energy of this massive boomer generation to meet the pressing needs of our children and frail elders in our communities. They stated that, last year, 470,000 RSVP volunteers provided 78 million hours of community service; Foster Grandparents provided 28 million hours of service to 264,000 children with special needs; and Senior Companions provided 14 million hours of service to 58,00 frail elders. They recommended that the 2005 WHCOA policy resolutions include the national senior volunteer programs to engage baby boomers in volunteer service and to increase federal funding to establish all three senior

volunteer programs in un-served areas and expand these programs to every county in the country.

30. **Martha Holstein**, representing the Health and Medicine Policy Research Group, presented the findings from their community forums in 2003 that identified the needs and expectations of older persons and family caregivers about long-term care and made the following recommendations: (1) the 2005 WHCOA should pose questions about the goals of our society for older persons who need help and explore questions of how long-term care should be enhanced; (2) explore risk-sharing and whether long-term care should be a private or a societal responsibility; (3) build a public constituency in terms of legislative and state reforms in the long term care system and budgeting process; (4) create certain guarantees for consumers purchasing private long-term-care insurance; (5) examine funding mechanisms for long-term care at the state level including a state tax; (6) adequately support family caregivers by building on the National Family Caregiver Support Program and (7) build incentives into the system to encourage people to use services as close to their homes as possible.
31. **Alan Factor** with the Rehabilitation Research and Training Institute at the University of Illinois at Chicago, recommended that the 2005 WHCOA address the needs of older adults with mental retardation and related developmental disabilities and their families. He stated that there are about 641,000 adults with developmental disabilities in the United States and that this population will double to 2 million by 2030. He added that there are an estimated 75,000 families on waiting lists to get residential services for their relatives with developmental disabilities. Research indicates that the most frequently reported unmet need was respite care for older parents caring for a son or daughter with developmental disabilities.

Closing Comments and Adjournment

Dr. Apparicio and Bob Blancato thanked the presenters for their testimony and requested supplemental written testimony in response to questions posed by Policy Committee members and to clarify issues raised during oral testimony. The Committee members requested the following:

- Executive summaries of reports on Research and Demonstration Projects cited in oral testimony;
- Follow-up written testimony with specific recommendations for further research and demonstrations;
- Research on naturally-occurring retirement communities;
- Research on the cost effectiveness of multivitamins in health promotion and disease prevention;
- Research on the projected workforce needs in the health professions for home health and hospice;
- Follow-up written testimony prioritizing recommendations on mental health and aging;
- Follow-up written testimony on transfers of funds among Older Americans Act Titles B “Supportive Services and Centers,” Title III-C-1 “Congregate Meals” and Title III-C-2 “Home Delivered Meals;”
- Follow-up written testimony on community planning efforts and programs to promote aging in place;
- Follow-up written testimony on the health status of baby boomers compared to the health status of previous generations.

The Listening Session was adjourned at 11:44 a.m.